

Internet use and preferences among women living with advanced breast cancer

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Abstract

Despite high distress and unmet informational and psychosocial needs, and recommendations for development of advanced breast cancer (ABC)-specific resources, there remains a paucity of appropriate, accessible psychological interventions. This survey study examined internet use and preferences of women with ABC, to the gauge feasibility of providing an ABC-specific internet intervention. Most participants (83%) used the internet daily. Results indicated most women with ABC would find an ABC-specific internet intervention helpful, and that it would address gaps in current internet resources, including provision of strategies to manage treatment side effects and fear of cancer progression.

Despite evidence of high levels of distress and support needs [1-3], individuals with advanced breast cancer (ABC) frequently report low rates of their needs being met; particularly health information and psychosocial needs [4-6]. Recommendations have therefore prioritised development of ABC-specific resources, including ABC-specific psychosocial interventions, to meet these needs [4].

Systematic reviews indicate a paucity of psychological interventions specifically for individuals with ABC [7, 8]. Our group's recent systematic review found while face-to-face group therapy had most evidence for efficacy, this was countered by lower accessibility and acceptability, demonstrated by low rates of uptake and adherence [8]. Low-intensity interventions had highest uptake and adherence [8], consistent with emerging trends in patients' desire for self-management [9, 10]. Both reviews recommended future research focus on development of accessible low-intensity / home-based interventions for individuals with ABC, including internet-based counselling [7, 8].

Despite growing evidence for the efficacy of online psychological interventions [11], evidence-based online interventions for ABC are yet to be developed. However, testing of web-based psychological interventions designed for *early-stage* cancer patients (e.g. [12, 13]) including breast cancer patients (e.g. [14]) consistently find improvements to quality of life and psychological distress [12-16]. Online psychological interventions therefore offer a promising platform for adaptation to the advanced setting. However, in order for such a platform to be adapted appropriately, adaptation needs to reflect current internet usage and content preferences of women with diagnosed with ABC.

Studies of internet use among women with early breast cancer report demographic predictors of use [17], its association with coping [18], use to seek medical information [19], and desire

to discuss such information with doctors [20]. However, no studies appear to have specifically examined internet use among women with ABC, nor these women's preferences for an ABC- specific internet intervention.

This paper reports on a cross-sectional survey examining internet use and preferences for seeking ABC-related information and support among women with ABC to inform development of a tailored web-based intervention for such women.

Method

Participants

Participants were women with a self-reported diagnosis of ABC and who had internet access, recruited through Breast Cancer Network Australia (BCNA) Review and Survey Group and subsequent online promotion through BCNA.

Materials and procedure

An online survey to assess participants' internet use and preferences for seeking ABC-related information and support via the internet (available on request) was developed by EK, BK and LB and reviewed by all co-authors. Questions assessed (1) demographic information, (2) internet use (e.g. frequency, duration), (3) types/topics of ABC-related information and support sought via internet, and considered important, (4) coverage of various topics of information and support by existing internet resources and (5) preferences for a specific program.

Analysis

All survey responses were analysed descriptively (mean scores or frequencies).

Results

Participant response and characteristics

Of approximately 325 women reached by online promotion, respondents completed consent 56 times. Five separate responses were determined repeated responses and three were ineligible, leaving 48 participants. Participant demographics are reported in Table 1.

Participants were aged 34-76 years ($M = 57.4$, $SD = 11.1$) and most commonly identified as Australian, married, tertiary educated, and retired.

Patterns of internet use

Participants' internet use is reported in Table 1. Most reported daily internet use. Internet use specifically to seek ABC-related information or support was more varied; 41.6% used the internet for this purpose at least 2-3 times a week and the remainder engaging in such use once per week or less. A single session of internet use, ABC-related or otherwise, most commonly lasted 10-30 minutes.

Topics of information/support

Figure 1 shows numbers of participants *looking for* various topics of information and support, rating these topics as *important*, and rating them *well covered* by existing internet resources.

Topics of information and support most frequently sought and rated as important were similar. These were most frequently medical topics, specifically: information about and strategies to manage medical treatment and potential side-effects; medical information on breast cancer and its symptoms; and information about and strategies to manage making medical decisions.

Psychosocial topics were frequently sought after and rated important; particularly: information about and strategies to manage fear of cancer progression; information about and strategies to manage the impact of cancer on emotional wellbeing; and strategies to cope with the impact of cancer on family and friendships. Information about and strategies for managing practical issues (e.g. financial impact), and planning for the future were also sought by sizeable proportions of participants.

Topics most frequently rated as *well covered* by existing internet resources included medical information on breast cancer and its symptoms and *information* on treatment and potential side-effects; *information* on the impact of cancer on emotional wellbeing was also rated as well covered by the majority of respondents. However, several topics of information and support that were frequently sought after and considered important were less frequently rated well covered; these included *strategies to manage* potential treatment side-effects, information about making medical decisions, *strategies* to manage the impact of cancer on emotional wellbeing, information about and strategies to manage fear of cancer progression, information about and strategies to manage practical issues, and information about and strategies for planning for the future.

Preferences for an ABC-specific internet intervention

Table 2 reports participant preferences for an ABC-specific internet intervention. While the majority currently found the internet at least ‘quite helpful’, most thought they would find an ABC-specific program ‘very helpful’. Participants indicated they would prefer to access such a program once or 2-3 times per week for 10-30 minutes. Program content participants were most commonly interested in included fact sheets and an online forum (Figure 2).

Discussion

This study suggests that while most women diagnosed with ABC use the internet and find it helpful when seeking ABC-related information and support, they experience gaps in information and support-seeking via existing internet resources and would find a specifically designed program helpful in meeting their needs.

Topics of information and support most frequently sought via internet and rated important reflected perceived importance of medical topics, consistent with literature on internet use in women with breast cancer [19]. However, findings suggest concerning gaps in existing internet coverage, particularly of *strategies* for managing treatment side-effects, rated well covered by only half of the participants despite more than three quarters looking for such strategies and rating them as important. Likewise, only a quarter of participants rated information on making medical decisions as well covered despite almost half rating such information important.

Similarly, information about and strategies to manage fear of cancer progression, sought and rated important by up to two thirds of participants, were rated well covered by less than a third of participants. *Information* on the impact of cancer on emotional wellbeing, and family and friendships appears sufficient. Despite this, *strategies* to manage the impact of cancer on emotional wellbeing and on family and friends were less frequently rated well covered, suggesting that some women with ABC are finding information on the impact of cancer on these areas but not strategies to manage this impact.

These findings indicate that addressing identified needs in health information and psychosocial domains [5] requires provision of *specific strategies* to help manage these impacts of ABC, and suggest potential for existing online interventions to be redesigned to meet these needs, as such interventions already provide worksheets and exercises aiming specifically to provide such strategies (e.g. [12]). An intervention adapted for ABC could also

address gaps identified in information and strategies currently available for managing practical issues and planning for the future, both of which are addressed for the curative setting in current interventions [12].

Participant preferences for interacting with/learning from others with ABC, particularly through group forums, videos and written stories, and for other interaction such as relaxation/meditation and quizzes, also suggest potential of adapting existing interventions that include similar content (e.g. [12]). Participants' comments on the need for specificity to ABC and a discriminating approach to currently available resources indicate the need for a legitimate, well-researched ABC-specific internet resource.

Limitations and directions for future research

This study specifically recruited through BCNA online promotion and is therefore likely to represent women with high levels of internet use and proficiency. However, such findings are likely to be representative of women most likely to use an ABC-specific internet intervention. While other interventions may be required by women with lower levels of internet access or proficiency, findings indicate that development of an ABC-specific internet intervention could be a fruitful direction for future research aiming to meet the information and support needs of women with ABC.

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Table 1.

Participant demographic characteristics and current internet use

Demographic characteristics	M (SD) or N (%)
Age (years)	57.4 (11.1)
Married/de facto relationship	41 (85.4)
Tertiary educated	28 (58.3)
Employed	10 (20.8)
Gross household income < \$80,000 (AUD)	28 (58.3)
Identified culturally as Australian	48 (100)
Internet use	N (%)
Average internet use frequency	
Daily	40 (83.3)
4-5 times/week	4 (8.3)
2-3 times/week	1 (2.1)
Weekly	2 (4.2)
< Fortnightly	1 (2.1)
Average <i>ABC-related</i> internet use frequency	
Daily	12 (25.0)
4-5 times/week	4 (8.3)
2-3 times/week	4 (8.3)
Weekly	5 (10.4)
Fortnightly	6 (12.5)
< Fortnightly	13 (27.1)
Not at all	3 (6.3)
Missing	1 (2.1)
Average internet use duration	
10-30 minutes	14 (29.2)
30-45 minutes	12 (25.0)
45 minutes – 1 hour	9 (18.8)
> 1 hour	12 (25.0)
Missing	1 (2.1)
Average <i>ABC-related</i> internet use duration	
< 10 minutes	3 (6.3)
10-30 minutes	24 (50.0)
30-45 minutes	11 (22.9)
45 minutes-1 hour	3 (6.3)
> 1 hour	3 (6.3)
N/A	3 (6.3)
Missing	1 (2.1)
Preferred device	
Computer	21 (43.8)
Tablet	15 (31.3)
Smart phone	6 (12.5)
No preference	3 (6.3)
Missing	3 (6.3)

Figure 1

Topics of information and support: Total number looking for topic, rating topics as important and rating topics as well covered by existing internet resources (N = 47)

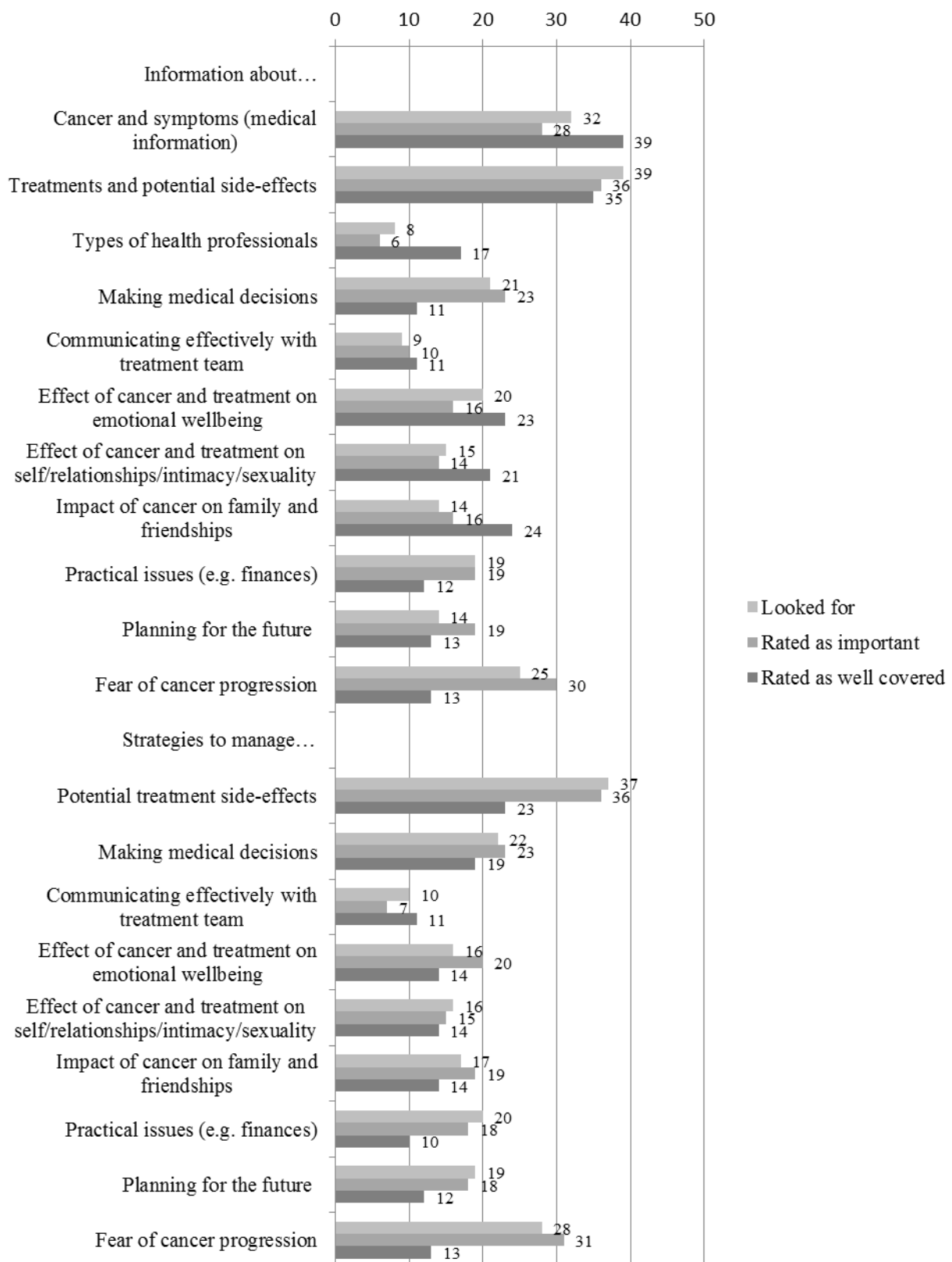


Figure 2.

Content preferences for an ABC-specific internet intervention

